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Five-year experience of clinical ethics consultations in a pediatric teaching hospital

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Five-year experience of clinical ethics consultations in a pediatric teaching hospital

Jürg C. Streuli · Georg Staubli · Marlis Pfändler-Poletti · Ruth Baumann-Hölzle · Jörg Ersch

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Abstract Our retrospective study presents and evaluates clinical ethics consultations (CECs) in pediatrics as a structure for implementing hospital-wide ethics. We performed a descriptive and statistical analysis of clinical ethics decision making and its implementation in pediatric CECs at Zurich University Children's Hospital. Ninety-five CECs were held over 5 years for 80 patients. The care team reached a consensus treatment recommendation after one session in 75 consultations (89 %) and on 82 of 84 ethical issues (98 %) after two or more sessions (11 repeats). Fifty-seven CECs recommended limited treatment and 23 maximal treatment. Team recommendations were agreed outright by parents and/or patient in 59 of 73 consultations (81 %). Initial dissensus yielded to explanatory discussion or repeat CEC in seven consultations (10 %). In a further seven families (10 %), no solution was found within the CEC framework: five (7 %) required involvement of the child protection service, and in two families, the parents took their child elsewhere. Eventual team–parent/patient consensus was reached in 66 of 73 families (90 %) with documented parental/patient decisions (missing data, $n=11$). Patient preference was assessable in ten CECs. Patient autonomy was part of the ethical dilemma in only three CECs. The Zurich clinical ethics structure produced a 98 % intra-team consensus rate in 95 CECs and reduced initial team–parent dissensus from 21 to 10 %. Success depends closely on a standardized CEC protocol and an underlying institutional clinical ethics framework embodying a comprehensive set of transparently articulated

values and opinions, with regular evaluation of decisions and their consequences for care teams and families.

Keywords Pediatric ethics · Parental authority · Best interests of the child · Decision making

Abbreviations

CEC	Clinical ethics consultation
CPS	Child protection service
DNR	Do not resuscitate
QALY	Quality-adjusted life year

Introduction

High-quality pediatrics requires high-quality ethics. Decisions on complex physiological and psychological issues within the therapeutic triangle of child, parents, and experts raise challenging ethical questions [2, 4, 6, 14, 31]. Insufficient reflection on, and communication of, values and facts can result in frustration, stress, and unsatisfactory decision making [20, 21].

Clinical ethics consultations (CECs) aim to tackle critical individual problems in a timely fashion, clarify the relevant medical facts, identify the ethical core issues (along with any other sources of conflict), and place them in a systemic value- and principle-grounded context. They then develop appropriate courses of action with due regard to the ethical and legal setting. The final step consists of well-documented implementation involving all stakeholders and meticulous follow-up [10, 19, 22, 26].

CECs are interventions with side effects and interactions. Although widely used, they have prompted few studies quantifying their contribution to clinical practice. The purpose of the present study, undertaken in a Swiss university children's hospital that had devised a dedicated clinical ethics structure

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one decade previously, was to review all clinical ethics consultations held over a 5-year period in order to determine whether ethical decision making could be further improved and, if so, how. We also propose further research and follow-up studies to develop better quality standards for the clinical implementation of clinical ethics services.

Methods

Background

An early model of clinical ethics consultations in pediatrics was developed in 1994 at the University Hospital of Zurich. CECs take place within an overriding Ethics Forum framework designed to foster an ethical dimension to clinical practice [10]. The core group in an Ethics Forum consists of 13 interdisciplinary healthcare professionals meeting on a regular six-weekly basis under the guidance and/or supervision of a medical ethicist. Working in a manner similar to an institutional review board, their responsibilities include education, advanced training, consultation debriefing, drafting of guidelines and recommendation templates, and the conduct and oversight of the CECs that are themselves but one part of an overarching ethics structure designed to establish an institution-wide ethics culture.

The CECs themselves proceed according to a predefined multistep model facilitating moral inquiry, deliberation, and consensus. Their aim, on an individual healthcare issue, is to come up with a recommendation that has been developed and endorsed by the whole team, patient, and/or parents. At the same time, they are designed to facilitate implementation of the recommendation by communicating, mediating, and continuously reviewing information exchange within the therapeutic triangle over the longer term. The format is that of a 60- to 90-min round table that can be—other than the core group—convened ad hoc within 48 h, potentially triggered by all professionals, patients, and parents confronted with an ethical question. The meeting follows two slightly different multistep models based on the two sets of environments and needs in our hospital: a seven-step open-outcome general pediatric model and a more structured intensive care model focused on maximal versus limited treatment (Fig. 1). Both include a moderator (provided by the core group) and professionals directly involved in the patient's care (inner circle) as well as experts, including a representative of the department head, who are relevant but not directly involved (outer circle). Both models require a consensus from the inner circle. The outer circle's function is advisory, while the department head's representative retains a power of veto (Fig. 2). The number of participants during a CEC varies from 6 to 14 persons, depending on the number of disciplines and team members involved. Basically, every professional who can contribute information concerning the associated problems and facts is invited. Once the care team (inner circle) reaches a consensus

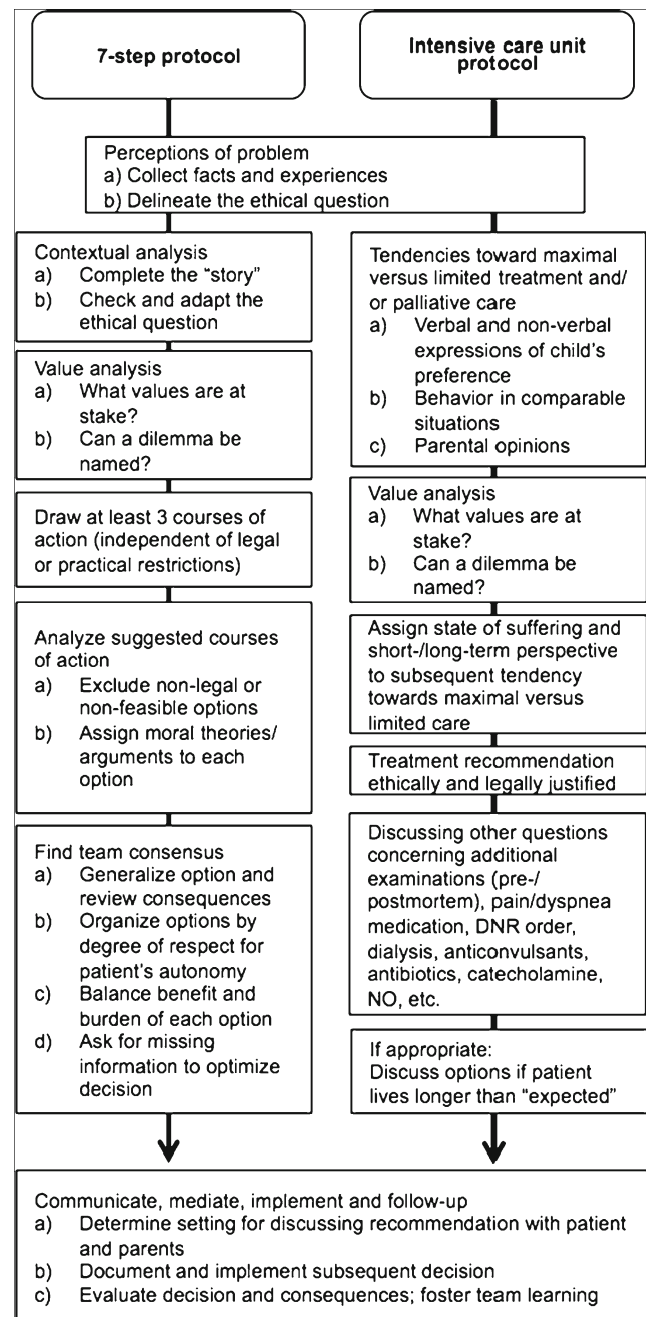


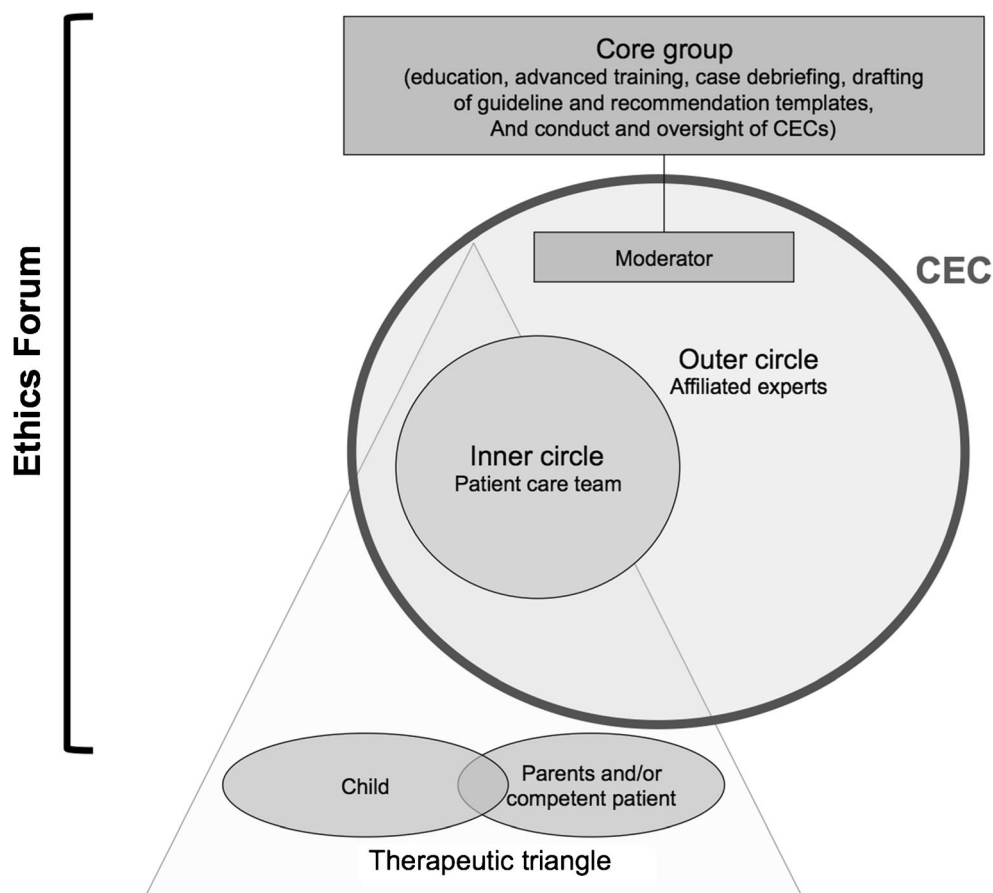
Fig. 1 Zurich models of pediatric ethical decision making

on a recommendation, it is a central task of a CEC to clarify how and by whom the resulting recommendation will be presented to the parents and/or the patient. In case of disagreement, the care team will repeat a CEC. The care team then has to find a new consensus, which may result in the acceptance of a split decision or in the involvement of the child protection service [8, 9].

Study population

We examined the records of all CECs conducted between 1 January 2006 and 31 December 2010 at the largest children's

Fig. 2 Components of the ethics forum and composition of the inner and outer circles in the Zurich clinical ethics consultation model



hospital in Switzerland. In 2010, the hospital had 218 beds (medicine, $n=72$; surgery, $n=60$; intensive care/neonatology, $n=39$; rehabilitation, $n=47$) occupied by 6,889 patients over 66,228 inpatient days (average stay, 9.6 days; average bed occupancy, 87 %).

Study instruments

Patient/parent characteristics, problems, preferences, and principles; CEC recommendations; and, if available, the patient's subsequent progress and outcome were tabulated in Excel 2010 (Microsoft Corporation, Redmond, WA) and analyzed using SPSS (version 19.0.0.1, IBM Company, Armonk, NY). The information was anonymized prior to tabulation. Inquiries and consultations conducted outside the CEC setting, e.g., at the bedside, by telephone, or in the core group, were not included.

Results

Patient characteristics

There is a slight but not significant male preponderance (56 %). Twelve patients had more than one CEC, at intervals of a few days to several months, for the same or a new ethical

issue ($n=9$ and $n=3$, respectively). Seven CECs were repeated due to failure to reach a team consensus; nine others were repeated because parent preferences were incompatible with the resulting recommendations. One patient had four CECs; the remainder, two. Half of all CECs were held in the first year of life (17 %, neonates <4 weeks; 36 %, babies 4 weeks to 1 year). Median patient age at CEC was 10 months (range, 1 day–25 years; Table 1).

Most of the 95 CECs were convened for critically and acutely ill patients ($n=68$) and few for already palliative situations near the end of life ($n=5$). Prognosis in terms of quality of life and length of survival was considered slightly to moderately compromised in 23 patients and good in none. The most frequent diagnoses prompting a CEC were congenital syndromes ($n=32$), perinatal brain damage ($n=14$), and cardiopathy ($n=12$). Most CECs were held in the intensive care unit ($n=58$), 13 in the long-term care ward of the rehabilitation unit, and between 2 and 4 each in nine other settings.

Problems, preferences, and principles

The most frequent issues concerned the withdrawal or withholding of a specific treatment ($n=42$), treatment goals, and the suitability of specific treatment intensities or types of treatment ($n=34$). Eleven CECs concerned the question for or against a

Table 1 Demographic, clinical, and administrative characteristics of the 80 patients discussed at the 95 clinical ethics consultations (15 repeats) at Zurich University Children's Hospital between 1 January 2006 and 31 December 2010

	<i>n</i> (%)
Sex (M/F) of patients (<i>n</i> =80)	45/35 (56/44)
Age at CEC (<i>n</i> =95)	
Newborn <4 weeks	16 (17)
Baby <1 year	34 (36)
Child 1–5 years	14 (15)
Child 6–12 years	15 (16)
Adolescent >13 years	16 (17)
Prognosis (<i>n</i> =95)	
Precarious/diminished QALY	23 (24)
Poor/severely diminished QALY	67 (71)
Terminal	5 (5)
Diagnosis (<i>n</i> =95)	
Congenital syndrome	32 (34)
Perinatal brain injury	14 (15)
Cardiopathy	12 (13)
Progressive CNS disease	7 (7)
Severe infection	7 (7)
Malignancy	5 (5)
Multi-organ failure	5 (5)
Traumatic brain injury	5 (5)
Immunological problem	2 (2)
Inborn error of metabolism	2 (2)
Lung disease	2 (2)
Tissue disease and bone	2 (2)
Departments	
ICU	58 (61)
Rehab	13 (14)
Oncology	4 (4)
Bone marrow transplantation	4 (4)
Nephrology	3 (3)
Neonatology	3 (3)
Immunology	2 (2)
Respiratory medicine	2 (2)
Mixed units	2 (2)
Surgery	2 (2)
Outpatient setting	2 (2)

CNS central nervous system, ICU intensive care unit, QALY quality-adjusted life year

“Do not resuscitate” (DNR) order. In 79 sessions, at least one secondary issue was present, mainly conflict within the treatment team (*n*=21), projected quality of life (*n*=20), treatment appropriateness, and treatment goals (*n*=18; Table 2).

In one third of CECs (*n*=31), parent preference was for maximal treatment; in 13 sessions, the parents opted for as

Table 2 Contents and issues debated at 95 clinical ethics consultations (15 repeats) at Zurich University Children's Hospital between 1 January 2006 and 31 December 2010

	<i>n</i> (%)
Main issue	
Withdrawing or withholding treatment	42 (44)
Appropriateness of treatment, goals of care	34 (36)
Resuscitation issues (“do not resuscitate” orders)	11 (12)
Quality of life	2 (2)
Allocation of resources	1 (1)
Disagreement team–parents	1 (1)
Legal–ethics interface	1 (1)
Patient autonomy	1 (1)
Family conflict	1 (1)
Staff or professional conflict	1 (1)
Secondary issue	
Disagreement team–parents	21 (22)
Quality of life	20 (21)
Appropriateness of treatment, goals of care, futility	18 (19)
Withdrawing or withholding treatment	5 (5)
Resuscitation issues (“do not resuscitate” orders)	4 (4)
Family conflict	4 (4)
Staff or professional conflict	3 (3)
Allocation of resources	3 (3)
Patient autonomy	1 (1)
No secondary issue	16 (17)
Parents' preference	
Maximal treatment	31 (33)
“Healthcare professionals should decide what's best”	19 (20)
Not to harm, no suffering	13 (14)
Unsure or discordant	10 (11)
Minimal treatment	6 (6)
More intervention than team, using alternative medicine	2 (2)
Palliative care	2 (2)
Letting child die	1 (1)
No data	11 (12)
Patient's preference	
No data	85 (89)
“Get treatment, get healthy”	3 (3)
Wants no further treatment	2 (2)
Unable to form an authentic preference	2 (2)
In accordance with the team	1 (1)
Wants to be with parents	1 (1)
Will be asked after the meeting	1 (1)
Dilemma	
Beneficence/non-maleficence	88 (93)
Autonomy/beneficence	2 (2)
Beneficence/distributive justice	1 (1)
Autonomy/distributive justice	1 (1)
No dilemma described	3 (3)

little suffering as possible for their child. Twelve parents wanted to have the healthcare professionals to decide for them and ten parents were unsure of or in disagreement about their own preferences. There was no correlation between patient preference and native or non-native Swiss background (Pearson's $\chi^2=1.14$, $df=1$, $P=0.29$).

Parent preference, indication of wishes, and expression of opinion were documented in 84 of all CECs. Patient preference was assessable and documented in ten CECs. Patient autonomy (the right to hold views, to make choices, and to take actions based on personal values and beliefs) was part of the dilemma in three consultations. Conflict between the principles of beneficence (the positive requirement of providing benefits to someone) and non-maleficence (the negative prohibition of actions or influences causing harm) was by far the most preponderant ethical dilemma (93 %).

Recommendations and outcome

CEC recommendations limited curative treatment in 57 of 95 consultations (palliative/comfort care, $n=26$; DNR order, $n=17$; submaximal optimized treatment, $n=9$; withdrawal of life-saving treatment, $n=4$). Maximal treatment was recommended in 23 consultations (Table 3).

The inner circle achieved a consensus after one session on 75 of 84 different issues (89 %) and after two sessions on seven issues (8 %). In two patients, there was no second session after dissensus due to the patient's early death.

Fifty-nine parents (81 %) agreed outright with the team recommendation. Seven families (10 %) initially dissented before consenting after explanatory discussion or one further CEC ($n=6$) or three further CECs ($n=1$). CECs failed to reach a solution in seven other families (10 %): five families (7 %) required the involvement of the child protection service, and in two families (3 %), the parents took their child elsewhere with no legal repercussions. Follow-up on the basis of the available medical history was only possible in 45 (56 %) of 85 patients: 29 (64 %) died before discharge, 5 (11 %) died shortly after discharge, and 11 (24 %) were alive at data assessment. The power of veto by the department head's representative has not been used in any case.

Discussion

We present the Zurich Ethics Forum approach to structuring a hospital-wide ethics culture and offer detailed statistical analysis of its implementation in 95 consecutive pediatric clinical ethics consultations. Care team consensus reached 98 % and parent/child–team consensus 90 %.

To our knowledge, our paper offers the largest retrospective analysis of CECs in the pediatric literature. In comparison to

Table 3 Resolution and outcome of the 95 clinical ethics consultations (15 repeats) at Zurich University Children's Hospital between 1 January 2006 and 31 December 2010

	<i>n</i> (%)
Resulting recommendation ($N=95$)	
Full treatment	23 (24)
Differentiated treatment	57 (60)
Palliative care	26 (27)
“Do not resuscitate” order	17 (18)
Optimized submaximal treatment	9 (10)
Withdraw life-saving treatment	4 (4)
Differentiated resuscitation	1 (1)
Other	13 (14)
Talking with patient	5 (5)
Collecting more information	2 (2)
Talking with parents	2 (2)
Child protection service	1 (1)
Optimized treatment	1 (1)
Exploring new options	1 (1)
No resulting recommendation	3 (3)
Time to team consensus	
One meeting	75 (89)
Two meetings	7 (8)
Dissensus without new meeting	2 (2)
Total excluding repeats ($n=11$)	84 (100)
Time to team–parent/patient consensus	
One meeting	59 (81)
Two meetings	6 (8)
Four meetings	1 (1)
Dissensus and involvement of child protection service	5 (7)
Dissensus and removal of child from hospital	2 (3)
Total excluding repeats ($n=11$) and missing data ($n=11$)	73 (100)
Follow-up	
Died in hospital	29 (64)
Alive according to last entry	11 (24)
Reported death shortly after discharge	5 (11)
Total excluding repeats ($n=15$) and missing data ($n=35$)	45 (100)

our 19 formal consultations per year, a survey in the USA from 1999 reported, among 275 general hospital committees, a mean of 8.1 formal consultations for both adults and children per year, with a median of 4 [27]. A German evaluation from 2002 to 2008 reported roughly three pediatric consultations per year [28]. Higher numbers were reported by a clinic of neonatology concerning exclusively end-of-life decisions in a uniform setting (e.g., 30 formal ethic meetings per year) using an earlier protocol of the Zurich Models of Pediatric Ethical Decision-Making [5]. Basically, hospitals have to balance a high number of formal ethic meetings against greater efforts, while higher numbers of consultations do not necessarily lead

to higher quality of ethical decision making. In our opinion, ethical decision making is a responsible process of cogent reflection leading to a weighty decision, which cannot be outsourced to a committee or an ethicist. To keep the process of decision making, the resulting decision, and its implementation close to all persons involved, a hospital must commit a certain amount of its scarce resources. According to subsequent qualitative interviews (data not shown here), most medical professionals think that 20 CECs per year in our hospital is a reasonable number. This certainly does not mean that the number could and should not be increased. However, the discussion is bound to further reflections about resource allocation and the importance of clinical ethics—a debate that our data can trigger, but not resolve.

Nevertheless, given individual needs and resources, the question arises of why and when a CEC is requested. DuVal [20] identified the most common factors triggering physicians' requests: (1) the need for help in resolving a conflict; (2) the need for assistance in interacting with a difficult family; (3) the need for help in making a decision or planning care; and (4) emotional triggers, such as intimidation, fear, or frustration. They concluded that these factors must be clearly identified so they can be properly addressed. However, our results suggest that the trigger does not have to be identical with the underlying ethical problem, nor does it have to play a central role in decision making. On the contrary, our findings suggest that intra-team and team–family conflicts exist in most consultations and—according to DuVal—may be fundamental in triggering a CEC. However, they were only of secondary interest in identifying the ethical problem and reaching a consensus about a solution. Given the very low number of team or team–parent conflicts discussed (team or team–parent dissensus was reported as a main issue in a single CEC) and the high rate of resulting consensus, we assume that the consensus culture in combination with moral inquiry and mediation based on human dignity and human rights does not only respect and absorb intrapersonal conflicts but also shifts the focus onto the ethical problem beneath.

However, the use of a closely structured model as presented here is controversial itself, mostly on the grounds that it reduces complex ethical issues to mediation practicalities where outcome is determined by preset team opinions based on hierarchy, culture, or reflex societal values [1, 7, 13, 29]. Theoretically, these are important objections, but the evidence in their favor is slight or nonexistent. To our knowledge, there are no data indicating that the outcomes of consensus-centered decisions are ethically or practically worse or that in-depth ethical inquiry by an ethicist would be a better way of reaching a “right and proper” decision in clinical practice. However, there are clearly limits to every consensus culture. Although an intra-team consensus rate of 98 % on complex ethical questions can be seen as a positive outcome [2], it remains an open question whether the Zurich model offers the

right balance between given structures and unbiased, ethically sound reflection.

Although we see prior team consensus as a key precondition for constructive discussion with the patient and/or parents, we also see the risk of inappropriate paternalism in a preconceived team opinion. Parent or caregiver tended in at least 19 consultations to place a decision in the hands of professionals by asking them to decide the best for their child. Moreover, parent preference was undocumented in 11 consultations. Behind these numbers, we assume a combination of simple documentation shortfall and parents overwhelmed by feelings of helplessness, ambivalence, anxiety, or guilt [33]. In our experience, there is a thin line between rash and unjustified handover of parental responsibility and overstraining the (evolving) capacities of parents to reach decisions in the tremendously difficult and unanticipated situations that occur on an ICU. At least one survey reported no evidence of parent inclusion in 27 % of pediatric ethics consultations, but the extent to which parental preference was considered was unclear [25]. To safeguard the patient or surrogate decision maker from potential paternalism, the CEC's duty must be to document the patient's and/or caregiver's values along with any subsequent conflict within the therapeutic triangle. Any recourse to the weight of a healthcare professional recommendation against, or instead of, an (initial) parental preference, and/or inclusion of the child protection service, should be justified in transparent detail (e.g., parental denial of blood transfusion or medication instead of moderate to good prognosis). Moreover, as parents might recognize a moral dilemma differing from that perceived by health professionals, CECs should offer repeated consultation if a moral dilemma is solved from the perspective of the team, but not from that of the parent or child [30]. Therefore, the influence of different clinical ethics approaches on the therapeutic triangle can and should be subject to continuous review, comparison, and critical reflection.

The realization that children not only can but also must be included in the decision-making process has gained increased acceptance in recent years [3, 12, 15, 16, 18]. Common ground can be found by agreeing the child's status as a subject, which implies the requirement for adequate protection and provision, and the consideration of the child's volition, with due regard for its corresponding and developing abilities [17, 24, 32]. Our sample contained mainly neonates, infants, and young children (62 %), many children in intensive care (60 %), and many critically ill children (72 %), who are rarely responsive. Given the very few children and adolescents involved actively in decision making (3 %), we are currently evaluating the use of age-appropriate participation facilitators such as expression of wish forms, computer questionnaires, diaries, and patient information documents, as proposed by Fraser et al. [23]. Whether thorough documentation of verbal and nonverbal expression of volition will include severely ill

children in a more active and comprehensive manner remains to be shown in further evaluation and research.

There can be no single conclusive answer to what constitutes “good ethical practice” in pediatrics. What is needed instead is a vigorous and constructive analysis of clinical ethics on different levels, including empirical data from patients, parents, and professionals, backed by theoretical reflection on norms, concepts, and methodologies. To create common ground, we propose pooling the clinical ethics requirements formulated by field leaders and working parties. For every CEC, we recommend the use of a comprehensive protocol covering the issue(s) at stake, the preferences expressed by the child and/or parents, the principles underlying the dilemma, the consensus recommendation, and the family’s reaction to that recommendation. Moreover, clinical ethics should entail continued education, evaluation, and quality management, designed to establish a practice-oriented culture of ethical reflection. Since bioethics emerged as a discipline in the early 1970s, it has been trying hard to translate ethical theory into clinical practice. Unfortunately, however, theory, once refined and simplified, becomes—or remains—largely unhelpful for specific clinical problems [11]. Both theory and practice must recognize their limitations and interdependence, and so far, no theory has been proven superior for clinical problems, and no form of clinical practice can claim impeccability. If excellence in clinical ethics is possible at all, ethical decision making should focus on a thorough integration of facts and values with practice-oriented recommendations and continuously evaluated exchange between all stakeholders. We hope that our data will foster constructive discussion on different approaches to these challenges.

Conclusion

Over the 5-year study period, transparent and comprehensible discussion achieved an intra-team consensus on treatment recommendations in 98 % of 95 ethically and clinically complex CECs and reduced parent–team dissensus from an initial 21 to 10 %. CECs lessen the tension between individual life designs and therapeutic or care options, but cannot fully eliminate it. Compromise is inevitable in the clinical application of ethics, with continuous evaluation of process, structure, theory, and quality at all levels within an organization offering the only safeguard, along with regular well-documented follow-up. In particular, we see four ways to ensure and to improve the quality of ethical decision making. Firstly, the process of decision making should be subject to complete and comprehensive documentation, including the values of parents, patients, and professionals. Secondly, if anyone in the therapeutic triangle does not communicate its

preference, circumstances and reasons should be documented and reflected as well. Thirdly, CECs are interventions with possible side effects and should undergo follow-up research, including its impact on families and professionals. And fourthly, the available resources and the number of CECs should be actively matched and critically reflected. The Zurich model is only one of many options for ethical decision making, and it goes without saying that willingness to critically question decisions and actions remains an absolute prerequisite for implementing an ethics culture within an organization and a great challenge for everyone involved. With our data, we hope to give impetus for further research on the implementation of clinical ethics and its effects on our patients, their families, and the involved professionals.

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